Province of British Columbia
Ministry of Health

SPECIAL ADVISORY COMMITTEE
ON
ETHICAL ISSUES IN HEALTH CARE

DEATH AND DYING AND THE LIVING WILL

July, 1989

DEATH AND DYING AND THE LIVING WILL

The Living Will is a signed declaration made by a competent adult that directs physicians regarding the type of medical treatment desired during the terminal phase of illness. The intent of the Living Will, the extent of studies of the Living Will, and the various problems in health care that it attempts to solve are covered in the three appendices attached.

The main thrust of the discussions held by the Committee was whether or not legislation making binding a Living Will would help patients in our particular society. There was no discussion of the validity of the concept of the Living Will, as it was generally accepted by the Committee as a very useful document and the exercise of completing such a document is of great value in most circumstances.

From the position papers and subsequent discussions, the Committee makes the following recommendations:

1. There appears to be no need in Canada for legislation making a Living Will binding in our health care system.

2. Education of the public in terms of what rights they have in our country as compared to others, (Appendix III) in terms of approving the treatment they are being offered must be improved by a planned program. The rights exist as is exemplified by the great variety of consent forms that patients must sign in health care institutions, but there is not sufficient knowledge of them by the general public. This does not mean that the Living Will is not important.

3. Health care providers must also be educated as to what rights are currently in place. The emphasis should be on the principle that one is never obliged to use disproportionate means (e.g., cardiac massage, shock, etc.) When imminent death is inevitable, one can take the decision not to use forms of treatment that would only secure precarious or burdensome prolongation of life.

4. If no other remedies are available, it is permissible, with the patient's consent, to use advanced techniques even if they are at the experimental stage or contain some risk, providing appropriate consent is well documented. With the patient's consent, these may be interrupted when the results fall short of expectations.

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5. A component of education for health care providers should be that one is not obligated to use more than the normal means of medications and one can avoid procedures and techniques which are particularly burdensome (e.g., a procedure or technique disproportionate to the results to be expected) without fear of litigation.

6. On no account should supportive care be discontinued on the basis of a physical or mental disability.

7. We endorse the guidelines contained in the Joint Statement of Terminal Illness (Canadian Nursing Association, Canadian Medical Association and the Canadian Hospital Association) of 1984, and look forward to modifications that are being developed to this document in the light of the experience obtained in its use. The Committee reviewed the report of the B.C. CASC of the Health Care of the Elderly and Long Term Care and felt it was a useful document.

8. Health Care providers should develop separate policies in conjunction with their consent forms which ensure that the wishes of patients or residents of Long Term Care Facilities about their care in emergency situations are documented when possible and available to the health care team.

9. We support the introduction of the proposed Health Care (Consent) Act (1988 Legislative program) which would allow persons while competent, to designate others to be their health proxies. (Appendix II)

10. We support the recommended changes to the Criminal Code of Canada by the Law Reform Commission (1983). These changes would make palliative care a simpler matter for Health care providers. (Appendices II & III)

11. We support the concept of preparing a Living Will in its present form, however we do not support its legislation. The health care provider must however be aware that a significant proportion of patients have no wish to confront their own mortality and their wish should be respected.

APPENDIX I

THE LIVING WILL

There appears to be no ethical problems associated with the concept that patients have the right to determine whether or not they should be treated at all or what type of treatment should be administered. This is accepted by all jurisdictions and is well documented in the many Consent for Treatment Forms, often with accompanying elaborate treatment protocols that patients must sign before treatment can be commenced. There does appear to be a problem in that some patients and possibly some physicians and nurses are not as aware of these patient rights as they should be.

How this awareness of patients' rights would be helped by some legal process is the main question we are facing. Some members of our society believe that by making the completion of a living will a legal necessity, the process would be helped, i.e., the Jack Bell Living Will Group. Some do not. The Law Reform Commission of Canada, in 1983, had major reservations of which we are all aware.

Our position, the ethical position, should attempt to support one or the other of these views.

Four documents are appended as being the most useful for this discussion; three papers, as well as the Joint Statement on Terminal Illness, 1984, prepared by the Canadian Medical Association, the Canadian Hospital Association and the Canadian Nurses Association, which has been distributed to all hospitals in Canada.

PROPONENTS FOR LEGISLATION

A summary of the arguments that have been developed are as follows:

- People are not aware of their rights as patients and are fearful of disagreement with their health care givers.

- Health care providers often find themselves in a position of uncertainty when an emergency arises in a seriously ill patient and are concerned as to their legal position.

- The legalization of the Living Will would encourage patients and doctors and families to clarify their intentions prior to an emergency taking place.

- Death with dignity would be more likely, as would appreciation of the quality of life that would be present after completion of treatment.

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THE OPPONENT

The rights of patients to refuse treatment and to tell the health care givers in advance of an emergency situation developing exists now and would not be changed by legalization.

The uneasiness of health care givers would be helped more by education in regards to the value of communication between doctor, patient and family and the nursing staff more than by legal maneuver.

To force patients to face up to the likelihood of death when they wish to avoid this realization, as many do, is really attempting to help the care giver rather than the patient.

Death with dignity and good palliation are already being recognized in our society by the rapidly increasing hospice movement. Education of medical students, nursing students, and other health care givers has, within the past five years, stressed this aspect of care in their curriculum.

By legalizing the need for a living will, people without one might be treated inappropriately to protect the health care giver.

The definition of terminal illness is extraordinarily difficult. It could be argued that as soon as one is born, one is terminally ill, as we all are sure to die. When patients develop heart disease or cancer, they could in many instances, be called terminally ill, even though they have many years of good quality of life available to them, with appropriate treatment. Forcing them to confront their mortality at this time is likely not good palliation.

RECOMMENDATIONS

1. The legalization of the living will, making it mandatory, would not appear sound from a reasoned and ethical position.

2. The use of the living will as one means of communicating the patient's wishes should be encouraged by health care providers.

3. Efforts to acquaint health care providers and the public with the existing rights of patients should be emphasized by all those involved with public education.

4. Subsequent quality of life should be a major factor in deciding the level of treatment when an emergency arises in a terminally ill patient.

5. The usefulness of the Joint Statement on Terminal Illness (1984) should be emphasized by some means regularly to nurses and doctors, in particular those parts of it devoted to better communication.

APPENDIX II

NATURAL DEATH/LIVING WILL LEGISLATION

ISSUE:

This paper explores the concept of the living will and implications of its legal recognition through natural death legislation.

BACKGROUND:

The living will is a signed declaration made by a competent adult that directs physicians, should that person become imcompetent, regarding the type of medical treatment desired during the terminal phase of illness. Most living wills direct the physician not to take measures that would prolong the patient's life.

The living will is an American invention devised in 1969 by the Euthanasia Educational Council. It is a manifestation of medical and social forces, the most prominent being the ability to prolong key physiological functions of life through modern biomedical technology. This has prompted the consideration of broader definitions of life, chiefly in terms of sentient, cognitive functioning, which in turn has led to increased concerns respecting patient autonomy.

Living wills first received statutory recognition in California in 1976. By 1985, 34 states and the District of Columbia had passed natural death laws. Most of these statutes contain the following provisions:

- recognition of the right of competent adults to direct physicians to withdraw "extraordinary" life-sustaining treatment in specified circumstances or terminal illness;

- terminal illness is defined as one which will result in natural death, whether or not life-sustaining procedures are used;

- the declaration remains in effect until revoked;

- the physician must be notified of the declaration, and;

- health professionals complying with the declaration are granted civil and/or criminal immunity.

There is no natural death legislation in Canada. There is also nothing which currently prevents an individual from executing a living will and hoping that his wishes will be respected.

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DISCUSSION:

A review of American literature discloses a continuing debate concerning the appropriateness and effectiveness of natural death legislation. The basic principle underlying such legislation is the common law rule that a competent person has the right to refuse treatment or to insist that treatment be discontinued. The physician's duty is simply to inform the patient of the available options and their consequences. Where the patient's decision is informed and freely given, then regardless of the reason for refusing or terminating a given course of treatment, the person's wishes should be respected.

If the patient is no longer competent, the first concern of the physician should be to determine whether the patient, while competent, indicated the nature of the medical treatment desired in the event of a particular medical diagnosis and prognosis. Absent statutory recognition, the living will is not binding, although it may have considerable persuasive effect.

Hence, the major argument in support of natural death legislation is that greater protection and scope is given to patient self-determination in the event of incompetency. Additional arguments are said to include:

- the establishment of guidelines for the initiation or withdrawal of treatment, thereby reducing misunderstandings;

- clarification of the rights of the patient and prevention of aggressive treatment of the seriously or terminally ill against his or her wishes;

- promotion of patient autonomy in deciding the extent of medical intervention, thereby absolving physicians and the patient's family from difficult decision-making;

- possible reduction of pain and unnecessary suffering;

- protection of physicians from civil and/or criminal liability; and,

- stimulating discussion of appropriate care while a patient is competent.

One additional advantage in British Columbia is the potential cost savings to the health care system if a patient's wishes respecting the withholding or withdrawing of extraordinary treatment were respected in every instance.

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However, experience with the living will indicates that it can also hinder clinical decision-making. Regardless of whether or not it is legally recognized, difficulties arise from the lack of precision in the language used and the difficulty of accurate prognostication.

Questions of interpretation are inevitable. The living will may not address many of the situations where guidance is needed. Lack of specificity in the wording may make it difficult to interpret what the patient's desires would be, given the particular medical condition. This, in turn, allows medical staff to reach differing subjective interpretations of a given statement, setting the stage for conflict and controversy. This problem would not be rectified by legislation since every case is unique and it is not possible to legislate a comprehensive guide for making medical decisions. However, the problem may be alleviated by discussion between physician and patient to clarify the patient's intention or, failing this, through the help of a close surrogate of the patient who can offer insight and interpret the patient's wishes.

The second problem arises in determining the patient's prognosis for recovery, especially in those cases where it can take several months for the ultimate prognosis to emerge. The conditions envisioned by the living will may not be capable of reliable prediction.

The Law Reform Commission of Canada recommended against the adoption of natural death legislation. The Commission believed that patient self-determination would more likely be eroded than reinforced. The very fact that a law is deemed necessary to assure patients' rights implies, and therefore tends to reinforce, the erroneous view that the patient does not have the right to refuse medical treatment. Thus, in securing rights for the small number of cases that fall within the scope of the legislation, the "natural" right to refuse treatment in other situations is jeopardized. This view has emerged in California where some physicians have refused to terminate aggressive therapies on terminallly ill patients where there is no living will or finding of brain death.

There are several alternatives to natural death legislation which could be explored, including:

- introduction of the proposed Health Care (Consent) Act (1988 Legislative Program). This legislation would establish a mechanism for providing substitute consent to the provision of therapeutic health care to a person who is incapable of consenting to the provision of that health care. It would also allow the patient, while still competent, to designate another person to make treatment decisions on the patient's behalf.

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- development of policies and procedures to help deal with the issues surrounding terminal care in health care institutions.

- encourage physicians to discuss the issues surrounding terminal care with their patients;

- support the recommended changes to the Criminal Code made by the Law Reform Commission of Canada in 1983. These changes would, to a large degree, remove the possibility of criminal prosecution for the withholding or withdrawal of treatment from certain types of patients. The Code would formally recognize the principle that a competent person has the right to refuse or terminate treatment and that a physician acts legally if he does not prolong the dying process. With respect to an incompetent person, a physician would not incur criminal liability for withholding or terminating treatment that is not therapeutically useful and not in the patient's best interest. Furthermore, a physician would be able to administer palliative care to a terminally ill patient even if the effect of that care might hasten death. If implemented, these recommendations would not, of course, address potential civil liability for these actions. While there have been no civil actions against physicians in Canada for leither honouring a terminally ill patient's wishes or refusing to do so, there have been at least two cases is the U.S. where physicians were successfully sued for assault for not adhering to a patient's wishes.

CONCLUSIONS:

This paper constitutes a preliminary review. Before a recommendation can be made, further in-depth analysis of the advantages and disadvantages of natural death legislation and the alternatives is required.

APPENDIX III

LIVING WILL: TREATMENT OF TERMINALLY ILL

The Law Reform Commission, in its section "Euthanasia, Aiding Suicide and Cessation of Treatment" came to the following conclusions:

"1. The law should recognize the competent patient's wishes and respect them as regards the cessation or non-initiation of treatment.

2. The law should clearly state that a physician acts legally when he decides to terminate or not to initiate treatment which is useless or which no longer offers reasonable hope, unless the patient has expressed his wishes to the contrary.

3. The law should recognize that the prolonging of life is not an absolute value in itself and that therefore a physician does not act illegally when he fails to take measures to achieve this end, if these measures are useless or contrary to the patient's wishes or interests.

4. The law should recognize that a physician who continues to treat a patient against his wishes is subject to the provisions of the Criminal Code.

5. The law should recognize that the incapaciaty of a person to express his wishes is not sufficient a reason to oblige a physician to administer useless treatment for the purpose of prolonging life.

6. The law should recognize that in the case of an unconscious or incompetent patient, a physician incurs no criminal responsibility by terminating treatment which has become useless."

In its section on "Cessations and Refusal of Treatment", page 69 and 70, it states:

> "In considering the problem of the cessation of treatment, the Commission has studied at some length the approach taken by certain American states, such as California, and has weighed the possibility of suggesting the adoption in Canada of an equivalent to the "Natural Death Act".

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This option, however, has been rejected for the following reasons. We believe that it would risk the reversal of the already-estabished rule that there should be no duty to initiate or maintain treatment when it is useless to do so. The living will approach begins from the opposite principle, since it requires that the patient's wishes be formally expressed in writing in order to authorize the physician not to prolong that patient's agony and death. This approach may be arguable in the context and legal systems of California and other States, but we do not feel it is an arguable reform for Canada.

The decision to terminate or not to initiate useless treatment is sound medical practice and should be legally recognized as such. The law, then, should not begin from the principle that a doctor who fails to prolong life acts illegally, but rather from the principle that a doctor acts legally if he does not prolong life.

It is the Commission's view that this already recognized common-law principle can and should be clearly expressed within the existing Criminal Code. Similarly, to repeat in the framework of athe present document a suggestion contained in Working Paper No. 26, the Commission also proposes that criminal law should formally recognize in the Criminal Code the principle that a competent person has the right to refuse treatment or to demand that it be stopped.

In the case of a person who is incapable of expressing his wishes, the Commission proposes that the decision to halt or not to undertake treatment should be based on two criteria. The first is a criterion of a medical nature and concerns the utility or non-utility of the administration of treatment. The second criterion is based upon the wishes of the person prior to becoming incompetent, or upon his best interests, determined by others in the event that that person is not or has never been capable of expressing his wishes. The Commission believes the "best interests" of the person may in cases indicate the prolongation of life, but in others the cessation of treatment in order to protect the incompetent person's right to a peaceful death with dignity. In the event of a conflict between, for example, the physician and family, as to the best interests of the patient, the courts should be called upon, as they are today, to settle the dispute. **On this point, then, the Commission proposes the maintenance of existing law and practice.**

Finally, as regards the question of the administration of palliative care, the Commission believes that a doctor must never refuse to administer pain-killing treatment, drugs or similar forms of treatment to a terminally ill patient only because the effective pain-killing dosage may hasten death.

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Our Committee should state:

1. There is no need in Canada for legislation making binding a living will or the stipulations contained therein.

2. At the same time, education should be directed to health care givers and the public to the rights of a patient to "death with dignity".

3. The emphasis on the education should be on the principle that one is never obliged to use "extraordinary" or "disproportionate" means (e.g., cardiac massage, shock, etc.). When inevitable death is imminent, one can take the decision not to use forms of treatment that would only secure a precarious or burdensome prolongation of life. Indeed, here some so-called "ordinary" means may become "extraordinary".

4. However, we should emphasize that to withhold or discontinue "ordinary" treatment on the basis of a physical or mental handicap, particularly on the basis of "quality of life" is to make a subjective judgment on "quality" and discriminates against the physically and mentally handicapped.

5. That if no other remedies are available, it is permissible, with the patient's consent, to use advanced techniques, even if they are at an experimental stage or at a certain risk (e.g., chemotherapy, Barnie Clark). With the patient's consent, these may be interrupted when the results fall short of expectations.

6. Notwithstanding the above, health care givers should be educated that one is not obligated to use more than the normal means of medicine. One can avoid procedures and techniques which are particularly burdensome (e.g., a procedure or technique "disproportionate" to the results to be expected).

7. We endorse the Joint Statement on Terminal Illness (Canadian Nursing Association, Canadian Medical Association and the Canadian Hospital Association) of 1984 regarding "no resuscitation" orders.